Seizure 18 (2009) 665–671

Contents lists available at ScienceDirect

Seizure

journal homepage: www.elsevier.com/locate/yseiz

"It shouldn't be something that's evil, it should be talked about": A phenomenological approach to epilepsy and stigma

S. Kılınç[a,*], C. Campbell[b]

[a] School of Social Sciences and Law, The University of Teesside, Borough Road, Middlesbrough TS1 3BA, UK
[b] Zayed University, United Arab Emirates

ARTICLE INFO

Article history:
Received 10 May 2009
Received in revised form 2 September 2009
Accepted 10 September 2009

Keywords:
Epilepsy
Stigma
Knowledge
Awareness
Phenomenology
Qualitative research

ABSTRACT

Objective: The concepts of felt and enacted stigma (Scambler and Hopkins, 1986[1]) are well established in epilepsy research. However, more recent research tends to focus on either those doing the stigmatising or utilises quantitative methodologies, exploring daily occurrences of stigma for those with epilepsy. The current study aims to explore the concept of felt stigma in today's society, arguing that a return to a phenomenological approach would allow people with epilepsy to discuss issues of importance to them, seeing them as the experts on this concept (Byrne, 2001[17]).
Methods: Fifty-two people with epilepsy were recruited via an advertisement on the Epilepsy Action website, thirty of whom took part in a follow-up interview. The interviews were analysed following Lemon and Taylor's (1997)[22] phenomenological approach.
Results: Three themes emerged, surrounding issues of embarrassment of having the condition, non-disclosure of the diagnosis and misconceptions of the condition. These findings support previous research which argues that people with epilepsy perceive a stigma due to feeling different from the rest of society, meaning that they conceal their condition as a way of managing such stigma and thus need to renegotiate their social identity. Additionally, the moderating role of education in increasing knowledge of epilepsy, with a view to reducing felt stigma, was evident.
Conclusions: The findings indicated a need to promote epilepsy awareness programmes as a means of increasing public knowledge of epilepsy, with the aim of reducing felt stigma.

1. Introduction

More than 20 years ago, Scambler and Hopkins[1] proposed that stigma could take two forms for people with epilepsy; enacted or felt, with their research culminating in the development of the Hidden-Distress Model of stigma in epilepsy.[2] Supporting earlier work by Schneider and Conrad[3] it was argued that the perception of a stigma surrounding epilepsy was rarely triggered by an enacted incident of stigma in society. As such, it was posited that in an attempt to avoid potential enacted stigma, people with epilepsy concealed their condition in order to pass as "normal". In turn, such an approach leads to few enacted occurrences of stigma, confirming the efficacy of such concealment to the person with epilepsy.

Indeed, Goffman[4] discussed how certain conditions can offer the person the option of hiding their diagnosis as they attempted to renegotiate their social identity. Deaux and Ethier[5] considered how the onset of a condition such as epilepsy could result in people feeling distanced from the dominant social group (i.e. those without the illness), potentially leading to denial and non-disclosure of the diagnosis, although identity enhancement could also be witnessed once negotiation of identity was resolved. However, in terms of epilepsy, such negotiation and disclosure of the condition is argued not to be an event, rather a process of divulging the diagnosis to select people, whilst continuing to conceal it from others.[3]

Moreover, the existence of felt stigma has been identified in more recent epilepsy research, such as Jacoby[6] who discussed the impact of felt stigma in a group of people with epilepsy in remission. Furthermore, negative misconceptions of epilepsy and seizures prior to diagnosis have also been identified as contributory to felt stigma,[7] compounded by the unpredictability of seizure occurrence[8] and ultimately leading to reduced social interactions.[9] Such lack of knowledge of the condition in people with epilepsy, may in turn significantly impair psychological adjustment to the illness and quality of life.[10]

In terms of enacted stigma, the incidence appears to be low, with the general public being well informed of epilepsy.[11] However, there are gaps in public understanding, particularly regarding the prevalence of the condition and perceptions that

* Corresponding author. Tel.: +44 1642 384284.
E-mail address: S.Kilinc@tees.ac.uk (S. Kılınç).

1059-1311/$ – see front matter © 2009 British Epilepsy Association. Published by Elsevier Ltd. All rights reserved.
doi:10.1016/j.seizure.2009.09.001

people with epilepsy have personality problems.[11] Furthermore, Reno et al.[12] conducted an experiment in Spanish secondary schools where they hired an actor to act out a tonic clonic seizure. One group of children received information on how to deal with the seizure after they viewed it, subsequently portraying few stigmatising attitudes when completing the 'Stigma in Epilepsy' scale 6 months later. However, the group who viewed the seizure alongside derogatory comments about the person had a much more negative and stigmatising view of epilepsy at the follow-up, demonstrating how expressed, negative attitudes towards epilepsy can influence others' perceptions of the condition, potentially compounding enacted stigma.

Consequently, the concept of felt stigma is well supported in the literature, coupled with the identification of a more favourable view on epilepsy from the general population. However, misconceptions regarding elements of the condition and the potential for stigmatising reactions cannot be ruled out in wider society, as evidenced by researchers such as Paschal et al.[7]

However, since Scambler and Hopkins'[1] original phenomenological inquiry into the stigma surrounding epilepsy and Scambler's later review of the concept, placing it in the context of social structures,[13] much research regarding stigma has focused on those doing the stigmatising rather than those experiencing stigma, be it felt or enacted.[14] Furthermore, research which does focus on the person with epilepsy is either quantitative in nature or explores everyday occurrences of stigma.[15] It is argued here that such approaches cannot fully investigate the experience of stigma for people with epilepsy. Alternatively, qualitative methodologies can be used to develop a better understanding of the phenomena under investigation, providing the opportunity to explore the meaning for the participant and better understand the experience for the person. In turn, this method of research adds a richness to the data which is gathered.[16] Furthermore, phenomenological research aims to perform an in depth analysis of the meaning of the lived experience of a phenomena,[17] concentrating on investigating the reality for the person,[18] seeing them as the experts on the phenomena since they live it and experience it. Indeed, Scambler[19] argues that experiential knowledge of epilepsy is important in order to understand the condition in more depth, as theorists assert that the examination of the subjective reality of living with epilepsy has more to offer researchers than their objective reality, embracing the emic perspective towards research.[17]

Consequently, more than 20 years since the introduction of felt and enacted stigma, it was deemed necessary to revisit this concept again, adopting a phenomenological approach to the inquiry, particularly in light of the advances in medical care and support services available for people with epilepsy.

2. Aim

To explore the experience of stigma for adults with epilepsy using a phenomenological approach.

3. Methods

3.1. Design

A phenomenological approach was taken, using semi-structured interviews, as a means of addressing the issue of stigma, by allowing the participants to discuss their experiences of epilepsy from diagnosis to the present day. It is argued that such an approach places the participants in the role as the experts of their epilepsy, allowing their subjective reality of the condition to be explored in depth.[18] As such, the participants were allowed the opportunity to discuss issues of relevance to them, meaning that if issues surrounding stigma were revealed, they must, therefore, play an important role in their experience of the condition.[17]

3.2. Participants

Fifty-two adults diagnosed with epilepsy after the age of 18 were recruited from across the UK via an advertisement placed on the Epilepsy Action website. Their age range at diagnosis was between 19 and 57 years of age, with the duration of their epilepsy being between 11 months and 30 years. Although 12 participants reported that their seizures had been controlled for between 2 and 22 years, all of the participants were currently taking anti-epileptic drugs (AEDs). Follow-up interviews were conducted with 32 of the original participants, up to 1 year following their initial interview.

3.3. Materials

Two interview schedules were designed using a phenomenological framework as a means of exploring the experience of living with epilepsy in adulthood. The first interview took a broad approach to exploring the epilepsy experience, adopting an episodic structure in order to examine the experience of the condition from prediagnosis, through diagnosis and to the present day, thus contextualising issues raised by participants in terms of the holistic epilepsy experience.[20] As issues surrounding perceived stigma and epilepsy awareness were prominent in these initial interviews, the second interview schedule probed these topics further, whilst remaining faithful to the phenomenological philosophy of the participant as expert.[17] The second round of interviews also served as an opportunity to use member checking to enhance the trustworthiness of the findings.[21]

3.4. Procedure

The first round of interviews took 8 months to complete. Six months later, following a preliminary analysis of the transcripts, the second round of interviews took place lasting a further 6 months in duration.

3.5. Analysis

Once all of the interviews were transcribed, the phenomenological analysis was conducted, in accordance with the guidelines set out by Lemon and Taylor.[22] Once the first researcher had read the transcripts a number of times, significant statements regarding the experience of living with epilepsy and the time of diagnosis were extracted. Following this, the statements were examined to establish their deeper meaning, before grouping them firstly into subthemes and finally into themes. Although no sub themes were identified in the final analysis, each theme illustrated two opposing elements of the experience. This process of organising opposing categories into themes is illustrated in appendix two. The coding was examined in two ways to establish the trustworthiness of the final analysis. Firstly, the themes and subthemes were examined by the second author, who agreed with the coding. Secondly, member checking was utilised in the second round of interviews and through correspondence with the participants regarding the final themes.[21] None of the participants reported that the themes were inaccurate.

3.6. Findings

Three themes concerning felt stigma were evident from the participants' accounts of their lived experience of the condition;

namely misconceptions versus ownership of epilepsy, avoiding versus sharing epilepsy and embarrassment versus normalising epilepsy. Each theme illustrated a struggle to negotiate their role or identity within their social environment.

4. Theme one: misconceptions versus ownership of epilepsy

The participants discussed a series of misconceptions regarding epilepsy, which they assigned to both the general public and to themselves, prior to and during diagnosis. Firstly, participants felt that the public held many misconceptions about epilepsy which contributed to the stigma surrounding the condition. Some described how they felt the general public viewed epilepsy as a mental illness, whilst others discussed how people thought they were drunk or on drugs when they were having a seizure.

> "Em. . .I still think there's a stigma about it. That there's some sort of em, connection with mental illness and that epileptics are slow people. . ."

> "Now when I had them [seizures] outside all you heard from some people was 'is he drunk, is he on drugs?', as you were coming out [of the seizure] you could hear them saying it you know and I used to think, if I could stand up, first of all I'd give you a right hand under the jaw and say 'yes I am on drugs but its to try and prevent this'".

It was also felt that the public did not know enough about the different types of epilepsy and seizures, particularly absence and partial seizures. Consequently, such perceived lack of awareness was seen as contributing to the participants' perceptions of their identity, often leaving them feeling distant from what they perceived as "normal" within society.

> ". . .I mean if you go down on the floor and shake people know what's going on, they accept that but when you're just doing something stupid or talking a load of rubbish you know, they, they just think you're totally, that you're mad".

> "That's [absences] the reason why I take my drugs. That's worse than falling over, what I call grand mal, falling over. Worse than grand mals because grand mals, people identify that to epilepsy. No-one identified that [absences] with epilepsy and you just feel like the biggest lunatic in the whole world".

However, it became clear that such misconceptions were also held by the participants, although many did not recognise this prior to diagnosis. By asking them about their own knowledge of epilepsy before the diagnosis was made, many participants described it as a severe illness that would significantly affect their lives, particularly in light of the uncertainty of seizure occurrence and the impact that it may have on their lives.

> "Well I didn't know, scared because I didn't know, what it was, what, could happen any time. That's what it was, anytime".

> ". . .before erm. . .it sort of really didn't mean anything, it was just sort of this strange disease that other people had and, erm, I'd never really taken a great deal of notice of it, didn't know a lot about it at all. . .So when it happened to me it was like, major. I just thought, my life's over. I assumed my career would go. . .erm, I don't know why I thought that but I did, I just assumed that I wouldn't be able to go back to work to do what I did and so I was very depressed and very, very quickly".

For those who had witnessed someone having a seizure, there were conflicting accounts of how they felt about the condition. Some participants viewed epilepsy as a particularly negative illness, however, others did feel that their prior experience prepared them for being diagnosed themselves, although it is evident that central to this preparation was learning about the condition.

> "Yeah beforehand em, I would have thought em, it was a sort of terrible illness that would just, you know, ruin my life completely, em. . .There used to be a young lad who had epilepsy who lived near me and I remember sort of thinking, 'gosh, that's a really scary illness to have, it must be awful'".

> "I found it was quite a high proportion of the people I was working with em. . .had epilepsy so em, you obviously had to learn about it, which I suppose it prepared me, gave me really good preparation".

Furthermore, as participants learnt more about epilepsy and in particular their own epilepsy experience, they discussed accepting having the condition, knowing what to avoid and how to reduce the uncertainty of seizure occurrence.

> "Oh, I accepted it quite quickly. I think it was more just knowledge than er. . .At the time I was seeing a doctor but he died, he used to sit down with you and literally go through everything, why it happened, what's causing it, what triggers it, everything. That helps, it literally does, cos it puts your mind at ease, 'cos they've, if you know what the triggers are, you know what to avoid".

> "I just have to get my head around the fact that this is it and also work out what strategies, if any, I need to put in place and sometimes that takes quite a while. And then when I've worked out what strategies I need to put in place, it, all that stuff about recognising my triggers and realising what makes things worse and then putting the strategies in place".

Indeed, acquiring knowledge of the condition seemed to allow the participants to regain some sense of control over their situation. Although general epilepsy information was beneficial, the process of learning out their own form of epilepsy, their seizure triggers and the strategies which they could adopt in an attempt to reduce seizure occurrence or at least seizure impact, appeared to be the most beneficial form of knowledge for these participants.

> "Yeah, well if you knew a little bit about it and the symptoms, you know if I'd known about it other people would have as well and there wouldn't have been that sort of, em, stigma attached to it, so I think it would have been a bit easier in that respect".

In particular, this final quote illustrates how increasing awareness about epilepsy prior to diagnosis, and for others in wider society could potentially reduce the felt stigma surrounding the condition, as well as make adjustment to the condition easier for those diagnosed.

Consequently, for some participants the lack of awareness of the condition compounded the fear and uncertainty at diagnosis, through their association of epilepsy with negative public perceptions and the detrimental impact on their social and work lives. However, for some, experiential knowledge of and actively learning about the condition prior to and following diagnosis, helped them to adjust and regain some control over their situation

when their own epilepsy was diagnosed. However, the association of negative public perceptions of epilepsy and the fear surrounding the condition also led some participants to hide their condition.

5. Theme two: avoiding versus sharing epilepsy

Many participants described epilepsy as a hidden illness, discussing how no one would know they had the condition unless they had a seizure. Although it was recognised by some that this often made a seizure occurrence more dramatic, the majority of participants felt that the potential to conceal the condition meant they could be judged as a person and not as someone with epilepsy.

> "I would say the main thing about it is that its not visible, there's no physical appearance, its more dramatic when the symptom occurs and they have a fit, a seizure".

> "You know, its not like you're in a wheelchair or something like that, its not visible. It means that people judge you as a person before, you know, its not part of their first impression of you".

However, within this theme it became apparent that some participants contributed to the hidden nature of the condition. For some, this meant staying in their homes or avoiding certain situations. The impact of going out in certain public situations had profound effects on some participants, such as panic attacks due to the fear of seizure occurrence. However, participants recognised that they could not avoid social situations completely, needing to venture into social settings sometimes, although this only occurred when they felt they had no choice but to do so. Other participants, however, described their attempts to return to social activities, taking one step at a time, recognising that such situations were not such a threat.

> "Er, well I don't go out much, I'm like a hermit".

> "...I've had quite horrible panic attacks, so, I tend to avoid those situations, although I have travelled on public transport but only when its been really necessary and there's no other way round it, on my own".

> "I think I must have been off work for about 8 weeks, and then I thought I'd have to do something, it was just....just not good. So what I decided to do, I thought I would get on....I don't drive, I've never driven, and obviously I wouldn't have been about to drive anyway, but I thought I would get on the bus and just go to the next village and then actually go into the city. But then I thought no, rather than actually go into the city, I can't actually manage to do that, so that's what I did. I literally just went to the next village which is a mile and a half away, something like that, got off there, and then I walked back. I just kept doing that. I just kept going further you know. I'd go a bit further the next time".

On the other hand, a seizure in public was often associated with concern for the participants' own safety, in that others may not know what to do if they had a seizure. Alternatively, some felt a responsibility for not disrupting other people by having a seizure in their presence.

> "Whereas if I was somewhere and I was by myself, or even if I was out and about and I didn't know anybody and I had one [a seizure], you know, would anybody help me, you know or would I just be left erm...and its frightening really".

> "I think I was always worried that I might have a seizure at work and whereas before I wouldn't be anxious about going in work, I enjoyed my job and I suddenly became very anxious about going in because I was always frightened about having one there, which would interrupt, you know, everybody, affected everybody you know because there was only four of us on the nursery floor, if I had a seizure it took another person out as well as me".

The concealable nature of epilepsy lent itself well to allowing participants to withdraw from society and hide their condition. However, for some this was through the fear of uncertain seizure occurrence, whilst for others it stemmed from worry of the impact a seizure would have on those around them, as well as concern for their own safety. As such, the return to social activities was a long process of testing the water and disconfirming the negative consequences which they perceived would occur. However, many of the participants felt that epilepsy should not be worn as a label, opting instead for concealing their condition from others.

> "I actually got to the point where I'd go and lie in the disabled toilet on my own and hope for the best, you know and if I knew I was going to have one, I can get myself in situations now where I know I've got an escape route as it were".

> "I've got quite good at hiding it, not putting myself in the situation where people could tell. Its like a minefield, you've got to think one step ahead all the time, it does actually take your life over really, in a lot of ways".

It is clear from these quotes that actively concealing the condition took considerable effort and much planning. The concealment was first and foremost in the participants' minds, illustrating their determination to prevent others knowing about their illness. However, the impact of such strategies meant that having epilepsy took over their lives, increasing its negative impact. On the other hand, some participants did discuss how such non-disclosure could have a negative effect, although not directly in terms of their own lives, rather recognising that concealment could contribute to public misunderstanding of the condition.

> "Erm, well firstly you need to get out and proud about it basically. I think that would help a lot of people. If more people would admit to it and it wasn't hidden away and what have ya, that would help an awful lot. Its not going to go away and I think there are a lot more people have it than admit to it".

> "Now, well to me I'm not bothered. To me it doesn't bother me anymore. Yes people can say 'You're epileptic' and I say 'Yes, yes' because I don't have it as something bad, something what...I don't have that anymore. All those feelings have gone. I don't have it as a stigma or a setback, something to hold me back.

The process of disclosing the condition seemed to evolve over time, with the recognition that epilepsy does not have to be a negative illness which restricts people's lives. For some, sharing the diagnosis had no limits, letting everyone know that they had epilepsy, whereas others only felt the need to disclose in specific situations or if the topic was raised.

> "I tend to tell people, if they ask and if its important, erm...because outwardly I don't look any different..."

> "It is part of me now and I like, I like to always tell people, the people around and sometimes I feel like I go on about it too

much but erm, anybody's friends or people around, people they work with, they need to know. Erm. . .you know that because if they know I had epilepsy, you know and I suddenly had a seizure in front of them, I mean, that would scare them but at least they're prepared, they know that I have epilepsy and I've told them roughly how they can help".

As such, the act of disclosing the condition was not a single event, whilst for others it came with the acceptance that having epilepsy did not negatively affect their identity. Furthermore, disclosure was seen as a means of preparing others if a seizure occurred.

Overall, the hidden nature of epilepsy lent itself well to concealing the condition. Strategies included non-disclosure of the illness and distancing themselves from society. However, such concealment was often an arduous task which meant that others would not be prepared if a seizure occurred in their presence. As such, some participants began sharing their diagnosis once they recognised that having epilepsy was not a threat to their identity, although disclosure was not a single event. Additionally, others took steps to return to social activities, a long-term process of moving out of their comfort zones, testing if a seizure would occur or if they could deal with the situation alone. However, negative perceptions of self were also evident in the participant accounts, leading some to feel embarrassed about their condition.

6. Theme three: embarrassment versus normalising epilepsy

It was evident that the epilepsy diagnosis affected the participants' confidence, preferring to blend into the background and not be noticed. This was particularly centred around their perceptions of themselves during a seizure and the embarrassment of drawing attention to themselves during a seizure episode.

"I don't feel, you know, as confident as I used to be when I was younger, not at all. I'm very indecisive, yeah, it's [epilepsy] made me less confident and less decisive. I used to be quite an opinionated person, I try to keep quieter now".

"I just felt this is, I'm a reject you know, basically, I'm one of nature's rejects. . ."

"I think a lot of it was because I wasn't controlled [with medication] straight away. I just felt as though I was odd and people would know I was odd".

These quotes illustrate the negative impact which an epilepsy diagnosis could have on the self-image of the participants. Descriptions such as "odd" and "reject" depicted how the participants felt different from others in society, struggling to reaffirm their identity in light of the condition, playing a more passive role in social situations. However, reduction in seizure frequency appeared to resolve this issue. Indeed, other participants discussed how they were still a normal person although they had epilepsy, calling for an increase in public awareness; taking away the negative, debilitating perceptions of epilepsy and normalising the condition, with the recognition that a diagnosis of epilepsy could happen to anyone.

"I would love to help people, to get rid of this stigma and point at people and say to people who are supposed to be normal, 'it could be you. I was okay, so it could happen'. So trying to get rid of this stigma and say, you know, 'I look fine don't I? I'm normal', but then to tell them that I have epilepsy, you know".

Education in schools was called for by the majority of participants, expressing the need to tackle awareness of the condition with young people as early as possible. In addition, many participants felt epilepsy should be publicised more, highlighting how people with the condition could still be successful. However, it is important to note that many participants felt that they could not disclose their condition, but were unhappy at celebrities who also hid the fact that they had epilepsy.

"More education on it. . .I think its worth going into school and teaching kids, things like that. Epilepsy tends to be starting off at a young age rather than, you know. . ."

". . .and the rich and the famous who've got it, I mean alright, they're not particularly hiding it but they're not saying to people 'so what, look what I've done and I've got it', you know instead of having to be treated as idiots all the time or as if you are useless. . ."

Consequently, this theme highlights how an epilepsy diagnosis can challenge a person's identity and sense of self, reducing their confidence and engagement in social interactions. However, reduced seizure occurrence and the recognition that people with epilepsy are normal, seems to resolve the original embarrassment of the condition. As such, participants called for improved awareness of the condition in an attempt to normalise epilepsy and thus minimise the embarrassment that they had felt.

7. Discussion

The three themes illustrated that identity and seizure occurrence were key concerns for the participants, although learning about their own form of epilepsy and normalising the condition mediated the perceived negative impact of the illness. Across the themes, the participants can be seen to be attempting to renegotiate their role in society once an epilepsy diagnosis had been given. Firstly, they discussed their fear at diagnosis, stemming from their own perceptions and society's misconceptions of the illness, feeling that epilepsy was a severe condition which would limit their social and working lives. However, learning about their seizure triggers and experience allowed them some form of control over the epilepsy, recognising that it need not be a threat to their social roles.

As identified by Schneider and Conrad[3] concealment of epilepsy was prevalent in this group of participants. Furthermore, non-disclosure was again associated with the unpredictability of seizure occurrence and the embarrassment of having a seizure in public. However, this fear of public seizures was also related to concern for disrupting others around them; worry for their own safety in that they may injure themselves; or that those around them may not know what to do to help. It was clear that non-disclosure in these latter cases had little to do with perceiving that stigma is present in society, although there was a perception that the public were less aware of how to deal with someone who was having a seizure. Additionally, in keeping with earlier research[3] disclosure was not a single event for some participants, rather a process of divulging the condition to some people whilst continuing to conceal it from others. The distinction was made based on who needed to know, often for safety reasons. However, some participants discussed being "loud and proud" regarding their condition, imposing no selectivity in terms of who they shared their diagnosis with, arguing that public awareness could only be raised once people with epilepsy disclosed their diagnosis.

Finally, participants discussed the negative impact that the epilepsy diagnosis had made on their identity, feeling "odd" or "a

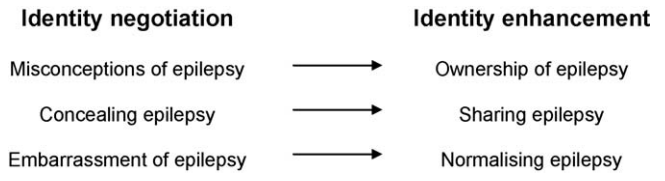

Fig. 1. Identity negotiation in epilepsy.[5]

reject", illustrating how they felt distant from others in society due to their condition. However, reduced seizure occurrence and the resolution of their social identity led many participants to call for increased awareness of the condition and a normalisation of epilepsy.

Overall, these three themes appear to support Deaux and Ethier's[5] work examining identity negotiation. It could be argued that the participants were negotiating their social identity when they discussed the restrictions on their social activities, concealment of the condition and the impact on their perception of self. Indeed, Goffman[4] introduced the concept of concealing a diagnosis in an attempt to renegotiate social identity. Successful identity enhancement[5] (see Fig. 1), therefore, would stem from learning about epilepsy and dispelling their misconceptions, resolving their identity and seeing themselves similar to others in society, ultimately disclosing their diagnosis and even promoting epilepsy awareness in society as a whole.

Consequently, despite advances in medical care and support services for people with epilepsy, more than 20 years after Scambler and Hopkins[1] introduced the concept of felt stigma, similar issues of concealment and embarrassment were evident in the current group of participants, spanning a range of ages, histories of epilepsy and locations in the UK. Indeed, Scambler[13] revised his earlier work on felt and enacted stigma, arguing that the model was incomplete. In particular, the biomedical focus and assumption that people with epilepsy are passive were challenged by Scambler and indeed the current findings, with the themes illustrating the active negotiation of social identity by people with epilepsy. As such, Scambler's re-framing of epilepsy and the findings from the current study indicate the need to further examine the stigma of epilepsy.

Additionally, a key finding in this study shows how participants' own misconceptions of epilepsy, prior to diagnosis, negatively impacted on their perception of self and social activities, a finding which is well supported in the literature.[7–9] Furthermore, increasing their own knowledge of epilepsy following diagnosis, helped to reduce their fear. Interestingly, as a means of tackling the unpredictability of seizure occurrence, learning about their own epilepsy was productive, leading to their acceptance of the condition. It is, however, important to note that although participants reported accepting their condition, they did not explicitly indicate that their self-esteem and participation in social activities were improved. Link and Phelan[23] considered how our culture can socialise us to hold negative perceptions of mental illness, which in turn can become "personally relevant" (pp. 373) when diagnosed with such conditions ourselves, leading to expectations of negative reactions. They considered that such socialisation could occur generically, not being confined to mental illness; indeed, such a theory does appear to be relevant to people with epilepsy. Consequently, future research could further explore the relationship between knowledge of epilepsy pre- and post-diagnosis, learning about their own form of epilepsy and felt stigma.

In terms of the limitations of this study, despite similar issues being identified across a range of participants, the time since diagnosis ranged between almost 1 and 30 years ago, meaning that the recollections of some participants may not be entirely accurate if they are recalling experiences from a number of years ago. Additionally, it can be argued that there is a danger of over interpreting qualitative data, an issue which the researchers sought to overcome through the process of member checking.[21] Finally, although the participants were not recruited from specific support groups, they were self selecting via an epilepsy support website and as such, may have had more issues to voice regarding their epilepsy than an entirely random sample may have done.

The findings from this study indicated that more time needs to be spent at diagnosis in order to help people come to terms with their condition and learn about their particular form of epilepsy. In addition, existing and future educational programmes, perhaps in schools, could reduce the potential for enacted stigma and also discourage concealment and felt stigma. This would be relevant should any of the children develop epilepsy in the future or if they were to know anyone who developed the condition. Ideally, therefore fewer misconceptions about epilepsy would abound. Although such programmes do exist,[24] they are often only promoted on websites, rather than via agencies actively approaching schools.

In conclusion, felt stigma remains evident with regards to epilepsy, compounded by issues of non-disclosure, embarrassment and reduced participation in social activities. Education may be the key to tackling this issue whereby increasing awareness in the general public may reduce the perception of stigma for those with the condition. However, when an epilepsy diagnosis is made, facilitating the patient to learn about their own condition, such as their seizure triggers and patterns, may also reduce problems in social participation, embarrassment and non-disclosure.

Acknowledgement

Many thanks go to Epilepsy Action for their support throughout the research process.

Appendix A. Excerpts from interview schedules

Interview one:

1. Can you tell me about life before you were diagnosed with epilepsy?
2. How would you describe yourself at this time?
3. How do you think others would have described you?
4. What did having epilepsy mean to you?
5. How did you think of people who had epilepsy?
6. What did it mean to be diagnosed with epilepsy?
7. What were the reactions of others close to you?
   a. How did this make you feel?
8. Can you tell me about your life now, following diagnosis
9. How would you describe yourself now?
10. How do you think others would describe you now?
11. What does having epilepsy mean to you now?

Interview two:

1. Can you describe someone with epilepsy?
2. What did you know about epilepsy before you were diagnosed?
3. Some people describe epilepsy as being restrictive, what do you think about that?
4. How well do you think you've coped with having epilepsy?
5. What do you think can be done for people with epilepsy?

Appendix B. Excerpts from theme summary table

Theme	Category	Example quotes
Misconceptions versus ownership of epilepsy	Misconceptions	*"Em…I still think there's a stigma about it. That there's some sort of em, connection with mental illness and that epileptics are slow people…"*
		"Now when I had them [seizures] *outside all you heard from some people was 'is he drunk, is he on drugs?', as you were coming out* [of the seizure] *you could hear them saying it you know and I used to think, if I could stand up, first of all I'd give you a right hand under the jaw and say 'yes I am on drugs but its to try and prevent this'".*
	Ownership	*"I just have to get my head around the fact that this is it and also work out what strategies, if any, I need to put in place and sometimes that takes quite a while. And then when I've worked out what strategies I need to put in place, it, all that stuff about recognising my triggers and realising what makes things worse and then putting the strategies in place".*
		"Yeah, well if you knew a little bit about it and the symptoms, you know if I'd known about it other people would have as well and there wouldn't have been that sort of, em, stigma attached to it, so I think it would have been a bit easier in that respect".
Avoiding versus sharing epilepsy	Avoiding	*"…I've had quite horrible panic attacks, so, I tend to avoid those situations, although I have travelled on public transport but only when its been really necessary and there's no other way round it, on my own".*
		"I've got quite good at hiding it, not putting myself in the situation where people could tell. Its like a minefield, you've got to think one step ahead all the time, it does actually take your life over really, in a lot of ways".
	Sharing	*"Erm, well firstly you need to get out and proud about it basically. I think that would help a lot of people. If more people would admit to it and it wasn't hidden away and what have ya, that would help an awful lot. Its not going to go away and I think there are a lot more people have it than admit to it".*
		"I tend to tell people, if they ask and if its important, erm…because outwardly I don't look any different…"
Embarrassment versus normalising epilepsy	Embarrassment	*"I don't feel, you know, as confident as I used to be when I was younger, not at all. I'm very indecisive, yeah, it's [epilepsy] made me less confident and less decisive. I used to be quite an opinionated person, I try to keep quieter now".*
		"I think a lot of it was because I wasn't controlled [with medication] *straight away. I just felt as though I was odd and people would know I was odd".*
	Normalising	*"I would love to help people, to get rid of this stigma and point at people and say to people who are supposed to be normal, 'it could be you. I was okay, so it could happen'. So trying to get rid of this stigma and say, you know, 'I look fine don't I? I'm normal', but then to tell them that I have epilepsy, you know".*
		"…and the rich and the famous who've got it, I mean alright, they're not particularly hiding it but they're not saying to people 'so what, look what I've done and I've got it', you know instead of having to be treated as idiots all the time or as if you are useless…"

References

1. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Sociology of Health and Illness* 1986;**8**:26–43.
2. Scambler G, Hopkins A. Generating a model of epileptic stigma: the role of qualitative analysis. *Social Science and Medicine* 1990;**30**:1187–94.
3. Schneider JW, Conrad P. In the closet with illness: epilepsy, stigma potential and information control. *Social Problems* 1980;**28**(1):32–43.
4. Goffman F. *Stigma. Notes on the management of spoiled identity.* Simon and Schuster Inc.; 1963.
5. Deaux K, Ethier KA. Negotiating social identity. In: Swim JK, Stanger C, editors. *Prejudice. The target's perspective.* Academic Press; 1998.
6. Jacoby A. Felt versus enacted stigma: a concept revisited. Evidence from a study of people with epilepsy in remission. *Social Science and Medicine* 1994;**38**(2):269–74.
7. Paschal AM, Ablah E, Wetta-Hall R, Molgaard CA, Liow K. Stigma and safe havens: a medical sociological perspective on African-American female epilepsy patients. *Epilepsy and Behaviour* 2005;**7**:106–15.
8. Morrell MJ. Stigma and epilepsy. *Epilepsy and Behaviour* 2002;**3**:S21–5.
9. Miller CT, Kaiser CR. A theoretical perspective on coping with stigma. *Journal of Social Issues* 2001;**57**(1):73–92.
10. Baker GA. People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma. *Epilepsy and Behaviour* 2002;**3**:S26–32.
11. Jacoby A, Gorry J, Gamble C, Baker GA. Public knowledge, private grief: a study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia* 2004;**45**(11):1405–15.
12. Reno AR, Fernandes PT, Bell GS, Sander JW, Li LM. Stigma and attitudes on epilepsy. A study with secondary school students. *Arquivos de Neuro-psiquiatria* 2007;**65**(Suppl. 1):49–54.
13. Scambler G. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory and Health* 2004;**2**:29–46.
14. Swim JK, Stanger C. *Prejudice. The target's perspective.* Academic Press; 1998 .
15. Swim JK, Cohen LL, Hyers LL. Experiencing everyday prejudice and discrimination. In: Swim JK, Stanger C, editors. *Prejudice. The target's perspective.* Academic Press; 1998.
16. Pope C, Mays N. Qualitative research: reaching the parts other methods cannot reach. An introduction to qualitative methods in health and health services research. *The British Medical Journal* 1995;**311**(6996):42–5.
17. Byrne MM. Understanding life experiences through a phenomenological approach to research. *AORN Journal* 2001;**73**(4):830–2.
18. Smith JA. Developing theory from case studies: self reconstruction and the transition to motherhood. In: Hayes N, editor. *Doing qualitative analysis in psychology.* Psychology Press; 1997.
19. Scambler G. Patient perceptions of epilepsy and of doctors who manage epilepsy. *Seizure* 1994;**3**:287–93.
20. Flick U. *An introduction to qualitative research.* Sage; 1998.
21. Lincoln Y, Guba E. In: Denzin NK, Lincoln YS, editors. *The handbook of qualitative research.* Sage; 2000.
22. Lemon N, Taylor H. Caring in casualty: the phenomenology of nursing care. In: Hayes N, editor. *Doing qualitative analysis in psychology.* Psychology Press; 1997 .
23. Link BG, Phelan JC. Conceptualising stigma. *Annual Review of Sociology* 2001;**27**:363–85.
24. Epilepsy Action. Epilepsy education information. www.epilepsy.org.uk/campaigns/awareness/primaryschools/.html; 2008.